

Patient Perspectives

Winter Contributors: William and Melanie Kelly

Patient Perspectives is a new feature in the newsletter that highlights vasculitis patient issues, our health care and our daily lives. If you have something you'd like to share about your experiences as a person living with vasculitis, please email Stacey LaBahn at jhvc@jhmi.edu or send a letter to:

The Johns Hopkins Vasculitis Center
ATTN: Stacey LaBahn
Bayview Medical Center
5501 Hopkins Bayview Circle
JHAAC, Room 1B.1A
Baltimore, Maryland 21224

Together we can make living with vasculitis easier by sharing our wealth of knowledge.

Going to Battle: One patient's strategies for winning the day, everyday

Mr. Kelly was diagnosed with Wegener's Granulomatosis in 1998. In caring for Mr. Kelly, first as a patient and then as a participant in a research study, those of us at the JHVC noticed how well Mr. Kelly's organizational skills helped him in coping with his illness and its complications. The JHVC asked Mr. Kelly if he would share his experience with our readers in his own words.



Since I have been afflicted with vasculitis and other maladies, I have had to come to terms with a new life style: medications, doctors' appointments, dietary alterations, and adjustments in quality of life. Not only does your lifestyle change when you have vasculitis; those of your family and loved ones may become altered radically, too. To manage the challenges of serious health problems, my solution was to come to terms with the new reality as quickly as possible. I knew I had to decide what I wanted to happen. When I first heard the news of the ailment, I experienced the five stages of grief: shock, disbelief, bewilderment, anger, and – finally – acceptance and resolution. The last phase, obviously, was criti-

cal; it helped me focus on controlling my health rather than allowing my health to control me. To move forward again and become healthy, I knew I needed a strategy. I started planning, which in many ways entails doing all the things that one might do in preparation for a battle. Here is my battle plan. (See opposite page for "Commander Kelly's Battle Plan.")

Melanie and I have lived "the word" of this "battle plan" and so we thought to provide a glimpse of how we have managed to live under the strenuous circumstances that have befallen us. I keep in mind that my maladies are my own and so it is my duty and my obligation to participate fully in the treatments prescribed by my doctors. That means do what they say to do and take the medications that they prescribe. In addition, I am obliged to speak up, to tell them when something that has been said or prescribed is not working, or it is causing pain or stress. Take responsibility, ask questions, and follow directions for your benefit. The more you know the better off you will be and improve the quality of your life.

The JHVC has posted on its website the medications chart and doctor/pharmacist list I've created for myself. (<http://resources/forms.html>). These documents can be saved to your computer and printed out for your own use. Ask a computer-savvy friend or family member if you need help. You can also ask for copies from the JHVC medical staff at your next appointment.☀

Can we be of service?

Please email us at JHVC@jhmi.edu or send your comments to:

The Johns Hopkins Vasculitis Center
c/o Stacey LaBahn
5501 Hopkins Bayview Circle
JHAAC, Rm. 1B.1A
Baltimore, MD 21224

Medications

Keep a simple medications chart:

- ◆ **A simple chart contains** your name, important contact information, a list of current medications that includes when you take them, how much you take, recent changes in normal dosage, and a list of any allergies.
- ◆ **Work to keep the chart as current as possible.** This will help you and the doctors “fine tune” the medications and track the effectiveness of new ones.
- ◆ **Post your medications chart on the refrigerator** or someplace else where you will be able to see it at a glance.
- ◆ For various **doctors’ visits, bring two copies of your medications chart** – one for you to write any changes on, the other for your doctor to keep. This will keep the doctors updated on your progress or changes.
- ◆ **Keep a copy of your medications chart with you** in your purse or wallet in case of emergency.

Stay on top of your medications:

- ◆ If you take several medications, **use the little 7-chamber pillboxes**, one pillbox for each time of day that you take your pills. I take medicine *three* times per day, so I have *three* 7-day pillboxes marked morning, afternoon, and evening.
- ◆ **Fill the pillboxes every week on the same day** to decrease the risk of running out of a pill or failing to notice that you need a prescription renewal.
- ◆ **Adjust your refills to coincide with each other**, so that you only have to worry about refills periodically. Check with your pharmacist to know their “busy days” to avoid delays in refills.
- ◆ **Take your medications as instructed** by the pharmacist or the instructions that come with the medication. I learned to take my medications with meals after ingesting some food. This has helped me avoid getting an upset stomach.
- ◆ **Learn all you can about your medications.** Pharmacists can give you a printout on every medication you take. Read that information and understand it.
- ◆ **Know the medications side effects and preventative actions**, such as “sun sensitivity” or “take with food.” It is important so you know if you are experiencing a side effect, how to react, and when to call the doctor if that is warranted.

Education

- ◆ **Learn all you can about your malady.** You may go on-line, ask your librarian, or find a support group for your disease. Your doctor can usually direct you to any of these groups or check the JHVC website at:

<http://vasculitis.med.jhu.edu/resources/links.html>.

Doctors and Pharmacists

Appointments:

- ◆ **Prepare for your appointment** by writing down any questions that have arisen during the period between visits.
- ◆ **Arrive 30 minutes before you are scheduled** to address any issues, (such as referrals, insurance issues, etc.) before being seen by the doctor.
- ◆ **Use a central appointment calendar for the household** to write down your appointments to prevent scheduling conflicts with members of the household.

Orders & Instructions:

- ◆ **Make sure you understand your doctor’s instructions.** The key word is: understanding.
- ◆ **Ask as many questions as you need** in order to understand what your doctor wants you to do.
- ◆ **Write things down.** We don’t always remember even though it seems clear at the time!
- ◆ **Keep a running record of events with your medications chart.** Track unusual pains, improvements, reactions; any nuances that occur to help you remember those events.

Medical Information:

- ◆ **Make a list of your doctors’ & pharmacies’ contact information**, such as names, addresses, specialty, phone numbers, fax, numbers, etc.
- ◆ Be sure that **your doctor has your permission through signed medical release forms to transfer your records** to any care provider necessary.
- ◆ **Ask about your medical records** so you feel confident all the information is present and correct. The medical staff can assist you in this process.
- ◆ If you wish, **keep track of your records** by asking doctor to note on the prescription or test requisition that you should be sent a copy of the report.

Personal Health Maintenance

- ◆ **Exercise** is very important to your recovery and quality of life. Start out easy and increase as you can, until it feels right.
- ◆ **Diet** is about quality of life. Your doctor or dietician will help you define your diet. Ask questions! Your medical condition can control what your diet should be (as in my case).
- ◆ **Knowing your personal objectives and life’s direction** is important to regaining control of your life. Now is the time to set some realistic goals and to strive very deliberately to achieve them. ☀